



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

The Honorable Dorcas R. Hardy
Chair, Policy Committee
White House Conference on Aging
4350 East-West Highway
Bethesda, MD 20814

June 8, 2005

Ms. Hardy,

Please accept the enclosed Resolution on Aging Caregivers and Adults with Developmental Disabilities on behalf of the Association of University Centers on Disabilities (AUCD) for consideration for the White House Conference on Aging.

Aging of the baby boom generation, the theme of the 2005 White House Conference on Aging, is a particularly relevant to the lives of people with developmental disabilities and their families. Medical, technological, and social advances have contributed to dramatic increases in life expectancy for individuals with developmental disabilities. Perhaps for the first time in history, the majority of adults with lifelong disabilities will reach ages similar to other baby boomers as they age.

However, increased lifespan has raised new issues. Over 75% of adults with developmental disabilities live at home with family caregivers. Many families need supports for both adults with disabilities and caregivers as they age. Furthermore, planning for the future when parents or other primary caregivers pass away or can no longer provide care is critical. Thinking about who will provide care to a loved one with developmental disabilities is a source of great anxiety for aging family caregivers who have devoted their lives to providing this care. Unfortunately, there are many systemic barriers and obstacles that make planning difficult, such as lack of available community-based residential supports.

AUCD is a network of more than 100 interdisciplinary, university-based centers. AUCD members represent every state and most territories in the United States. Our mission is to advance policy and practice for and with people living with developmental disabilities and other disabilities, their families and communities through research, education, and service to further independence, productivity, and satisfying quality of life.

Seeing the issue of aging caregivers and adults with developmental disabilities as an important area for the White House Conference on Aging to address, a network-wide workgroup has developed the enclosed resolution. In developing the resolution, we have drawn upon existing literature, identified barriers, and provided specific, implementable steps we feel can be taken to move from "awareness to action."

Thank you for the Policy Committee's consideration of this resolution for inclusion under "Our Community" on the agenda for the White House Conference on Aging.

Respectfully Yours,

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**RESOLUTION ON AGING CAREGIVERS AND ADULTS WITH
DEVELOPMENTAL DISABILITIES**

WHEREAS the aging of the United States population includes individuals with lifelong intellectual and other developmental disabilities; and

WHEREAS technological, medical, and social advances have contributed to dramatic increases in life expectancy for individuals with lifelong disabilities over the last century, making it now likely that baby boomers with lifelong disabilities will outlive their parents; and

WHEREAS over 75% of adults with lifelong disabilities live at home with family caregivers and more than a quarter live with aging caregivers over 60 years of age; and

WHEREAS adults with lifelong disabilities also provide reciprocal care, support, and companionship to their aging caregivers who face age-related declines; however, at times the family as a whole needs additional services and supports; and

WHEREAS coordinated one-stop systems of information and referral regarding aging and disability long-term services and supports are recent developments and still unavailable in many states; and

WHEREAS research demonstrates that individuals with lifelong disabilities, older individuals, and families desire increased flexibility in services, including options for consumer-direction and financial supports; and

WHEREAS families with relatives with lifelong disabilities incur out-of-pocket disability-related expenses, experience fewer opportunities for paid employment, and are less financially secure than other families; and

WHEREAS family support and lifespan respite programs can benefit a diverse range of families; however, an "institutional bias" in long-term care delivery limits access to such home and community-based services; and

WHEREAS half of State Units on Aging identify respite as the greatest unmet need of older families caring for adults with lifelong disabilities, followed by staff training on these types of older families and their future planning needs; and

WHEREAS long waiting lists for home and community-based residential services preclude other residential options for individuals with lifelong disabilities and pose barriers to planning for the future when aging caregivers can no longer provide care; and

WHEREAS planning for the future when aging caregivers can no longer provide care involves specific legal and financial considerations –such as special needs trusts, guardianship, and less restrictive protections –as well as future residential and lifestyle preferences; and

WHEREAS lack of family future planning can result in inappropriate residential accommodations, loss of intended inheritance, and jeopardized access to needed services for adults with lifelong disabilities as they age.

THEREFORE, BE IT RESOLVED by the 2005 White House Conference on Aging to support the following recommendations:

- Enhance the National Family Caregiver Support Program to make it more fully inclusive of aging caregivers of adults (age 19 and older) with lifelong developmental disabilities; and increase funding to accommodate the needs of these families and anticipated growth in overall need as baby boomers age.
- Provide increased opportunities for research and demonstration projects in the Older Americans Act on innovative supports for aging adults with lifelong developmental disabilities and family caregivers –such as consumer-directed supports and supports to minority families.
- Support legislation to assist states in developing lifespan respite programs for all families providing care to relatives with disabilities, regardless of age or type of disability –such as the Lifespan Respite Care Act.
- Support legislation to provide caregiver tax credits to enhance the financial security of families providing care to relatives with disabilities.
- Support legislation to correct the institutional bias in long-term care and expand home and community-based services and supports –such as MiCASSA, Money Follows the Person Act, and the CLASS Act.
- Support legislation to address the shortage of qualified community-based direct support workers –such as the Direct Support Professionals Fairness and Security Act and the Independent Living Assistance Access Act.
- Expand the Aging and Disability Resource Centers to every state and permanently authorize these centers in the Older Americans Act with language ensuring supports to adults with developmental disabilities and aging caregivers.
- Expand the Administration on Developmental Disabilities family support grants and develop a focus on supporting aging families.
- Provide funding for training on aging with lifelong developmental disabilities and future planning through joint initiatives between the Administration on Aging and the Administration on Developmental Disabilities.
- Provide increased information and assistance on future planning to aging families with relatives with lifelong developmental disabilities through the Aging and Disability Resource Centers, Administration on Developmental Disabilities Family Support grants, and other initiatives.

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